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ABSTRACT

This report discusses basic issues in the provision of residential services for people with developmental disabilities. Main points of the discussion include: (1) the service system for this population is in a crisis of accountability as meeting safety and quality requirements threatens to become counterproductive; (2) the current system is well defended against efforts to rethink and fundamentally reorganize it; (3) the perspectives of effective interdependence and systems thinking can assist in system redesign; (4) effective police power is needed to protect people with developmental disabilities from abuse and neglect; and (5) multiple, various, small scale, self-organizing systems of assistance in a field organized by principled negotiation and shared learning are needed. Other topics discussed are barriers to thinking deeply about accountability, integrity as a central virtue in effective interdependence, threats to integrity from the dominant pattern of quality assurance, dealing more effectively with failures of integrity, the potential contribution of Total Quality Management, and integrity as a guide to policy. (Contains references as footnotes.) (DB)

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perspectives
On Community Building

Assistance With Integrity

The Search For Accountability And The Lives of People With Developmental Disabilities

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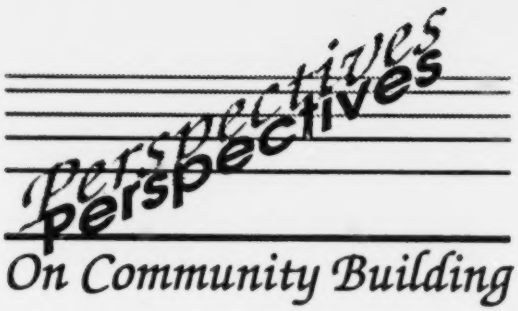

Reports in the Perspectives on Community Building series discuss issues of concern to those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life.

These papers are based on visits to innovative human service programs and focus group discussions. Program visits include intensive interviews with program leaders and staff, and usually with some of the people they assist. Discussions include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

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The problems of life are insoluble on the surface...
Getting hold of the difficulty deep down is what is hard.
Because if it is grasped near the surface it simply remains the difficulty it was. It has to be pulled out by the roots; and that involves our beginning to think about things in a new way. The change is as decisive as, for example, that from the alchemical to the chemical way of thinking. The new way of thinking is what is so hard to establish.
Once the new way of thinking has been established, the old problems vanish; indeed they become hard to recapture. For they go with our way of expressing ourselves and, if we clothe ourselves in a new form of expression, the old problems are discarded along with the old garment.

*–Ludwig Wittgenstein**

* Wittgenstein, L. (1980). *Culture and value*. Oxford: Basil Blackwell, p. 43.

A note on style and focus

This report is written as a polemic, a discussion intended to stimulate controversy and dispute. While this style has an honorable tradition in politics and philosophy, it is little used in the world of human services, where inquiry is mostly shaped by middle-of-the-road academic social science with its conventions of detached objectivity and quantification. Contrary to this more usual style, we will assert strong positions because, based on our experience, we believe them to be true and useful. We have been informed by the meetings and interviews noted on the cover page, but we have not been limited by them. We do not claim to be dispensing objective truth, but only to be telling the truth we can see from where we have been. We welcome thoughtful disagreement and evidence and perspectives we have missed.

Our primary focus is on people with developmental disabilities who rely on service providers for 24 hour assistance. Most of these adults and children live in regulated, group settings. A small but growing number live in a variety of types of supported living arrangements where service staff retain responsibility for decisions about how much direct staff contact, up to 24 hours a day, people will have. This paper will be less directly relevant to the situation of people with developmental disabilities who live with their families.

This report will be disappointing to people who want a few, practical, politically feasible recommendations that, if implemented, will assure the safety of vulnerable people while improving the quality and cost efficiency of the existing crazy mix of services. Of course, we will make suggestions that we think are practical. But we make them tentatively, as an aid to thinking and as an invitation to many small scale experiments, not as a grand program.

We have met many people deeply concerned about doing the right thing in company with people with disabilities. These people find meaning in struggling to better understand the ethics and the politics of their work lives, and they find discussions about compliance with rules and avoidance of sanctions beside the point. We don't want to join the cynical, who reduce everything to greed and power over others, in missing their point. So we may seem dangerously naive to people for whom civic life has collapsed into economics: a world in which narrow self-interest provides sufficient explanation for behavior, and material reward and punishment provide the only effective motor for policy. For them, our appeal to civic virtue will seem quaint if not disingenuous. But let the reader be warned: the civic virtue of integrity lies at the center of our argument.

Main points

- People with developmental disabilities rely on a service system that is in a crisis of accountability. Efforts to assure safety and quality have become activity traps that threaten the developments most necessary to improve the quality of community life for people with developmental disabilities. Investments in improving the mechanisms of quality assurance have become at best expensively irrelevant; at worst, they are counterproductive. It is this crisis of accountability that calls on concerned people to surface and reconsider their assumptions about assuring safety and quality (see the summary diagram on the next page).

- The current system is well defended against efforts to rethink and fundamentally reorganize it. Nevertheless, such redesign is necessary.

- Two perspectives contribute helpfully to this reconsideration: a perspective revealed by reflection on the experience of people with developmental disabilities who receive good support, summarized here as effective interdependence; and a perspective derived from systems thinking, which offers some useful guidance to the work of redesign.

- The perspective of effective interdependence reveals the virtue of integrity as the foundation for those developments now necessary to improve the quality of community life for people with developmental disabilities.

- Unfortunately, paid work with people with developmental disabilities has an enduring attraction to abusive, neglectful, exploitative, power hungry, and slothful people. While these people represent a minority of those working at any time, their influence can be devastating if it is not checked. Controlling the anti-social minority requires conscious, powerful efforts by people with developmental disabilities themselves and all those who care about their well being. Such efforts require an effective police power, which presupposes not only the capacity to discover and prosecute abuse and neglect but, at least as important, the capacity to strengthen the voice of people with developmental disabilities and the capacity to generate alternative living arrangements and alternative sources of necessary assistance.

- To flourish, the virtue of integrity calls on people to create multiple, various, small scale, self-organizing systems of assistance within a field that is increasingly organized by principled negotiation and shared learning. These two challenges define the leading edge of the work of building safer, more just, more inclusive communities in company with people with developmental disabilities.

Contrasting Responses to People's Vulnerability

Regulate

Inspect & correct

Current, Dominant Assumption: People with disabilities are passive, fragile objects with limited possibilities for personal relationships.

- People's needs can be adequately defined procedurally
- People's safety will result from requiring uniform application of policies by staff in whom the system makes the minimum possible investment; high turnover is assumed
- The way to improve quality is to improve organizational procedures
- There is no important conflict between improving quality and insuring safety by requiring uniform application of impersonal procedures

Emerging Assumption: People with disabilities are choice makers, who are capable of contribution and capable of forming rewarding relationships.

More opportunities

Risk management

Direction from seeking positive change & dealing with the risks & crises that follow

- People's capacities and needs can only be understood in the context of trusting relationships in which other people join them in responding to opportunities, problems and risks
- People's safety will be protected as much as possible through the quality of their relationships with family, friends, and staff and the extent to which they can exercise control of their life circumstances
- The way to improve quality is to invest in people's relationships and learning; quality improves through a variety of person specific actions
- There are frequent tradeoffs between safety and risk as people develop and as agencies and the system learn new capacities

Agencies need to...

- Increase ability to form effectively interdependent relationships under conditions of uncertainty, differences & conflicting ideas, high emotion, & low (initial) trust [in an effectively interdependent relationship a staff person identifies & responds to opportunities, problems & risks]
- Increase knowledge of possibilities, risks, & alternatives
- Money to arrange/provide necessary assistance
- A reliable process for providing everyday & unusual assistance

So that...

People have a growing number of alternatives to being/feeling trapped within a single service setting

People have increased capacity to effectively communicate their desires & problems

People have increased ability to negotiate & act along with others (friends, family, advocacy organizations)

Systems will need to...

Tools, frameworks, assistance, & money to encourage...

...agency openness to outside influence

...agency values, vision, & culture which support integrity: good relationships & positive action

...investment in staff competence & continuity

...resource flexibility

Effective ways to respond to abusive/neglectful situations and patterns of abuse/neglect

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A crisis of accountability

Services to people with developmental disabilities face a crisis of accountability. Uncounted thousands of hours of professional time and dollars of scarce public resources pour into enforcement of and compliance with increasingly complex regulations. Administrators and professional advocates join forces to assemble a truly comprehensive set of quality assurance mechanisms and activities. Debate about assuring quality and safety fills the pages of journals and swapping anecdotes about the absurd distractions imposed (and accepted) in the quest for compliance fills hours at professional meetings. In the name of entrepreneurial government, or a commitment to total quality management, system managers convene task forces of advocates, providers, and officials in order to slim and streamline regulations.

With all this activity, it is hard to find anyone who will admit to the belief that the present quality assurance system in fact assures that people with developmental disabilities live safely and in receipt of high quality assistance. But it is equally difficult to find people willing to actively experiment with letting go of the premises and practices that drive the current system ever deeper into counterproductivity.

Most people seem to oscillate between complaining about the quality assurance system's ineffectiveness and loading greater responsibilities onto it. Legislators, state managers, and courts delegate responsibility for improving the quality of services to inspection systems that recurrent scandals demonstrate have yet to prove their ability to even keep people safe. Conscientious inspectors question their effectiveness while at the same time seeking greater influence, either by finding ways to be more helpful to service providers or by requesting stronger sanctions with which to punish them. Representatives of advocacy organizations call for more exacting requirements and more extensive program oversight and justify their demands with accounts of the repeated failures of the existing system of oversight and regulation.

Alongside these debates about the administrative activities of quality assurance, a quiet revolution in the lives of a small but growing number of people with developmental disabilities redefines the terms of accountability. People with developmental

disabilities who get opportunities and necessary assistance to grow up in reasonably well supported families, to go to school alongside their non-disabled brothers and sisters, to work productively, to be an active part of the civic life of their communities, and to live in their own homes undermine the current logic of service delivery and thus the foundations of current activities to assure safety and quality. In new roles in new settings, more and more people with developmental disabilities emerge as having the same desire to author their own lives as anyone else does. So, if the service system's function is to promote human development, policies and practices which assume that people with developmental disabilities are passive objects of professional work must change.

People with developmental disabilities cannot survive and deal with the many serious life problems in these new settings without effective assistance. The strategic challenge now facing policy makers and practitioners lies in learning how to increase opportunities and focus assistance effectively on a growing variety of individual circumstances.

These pioneers and their allies set the test for every policy and service strategy, and so for any approach to assuring safety and quality. **The test is simple: does this activity increase service capacity to assist people with developmental disabilities in expanding their opportunities to participate in community life as they choose?**

The dominant share of existing policies and services respond to a different strategic test: does this activity increase capacity for the proper performance of bureaucratically specified professional work on people with developmental disabilities? Under this strategic challenge, activities to assure safety and quality focus on improving control of the professional work assumed necessary to repair (habilitate, rehabilitate, train) defective people. In this world, bad things happen to people with developmental disabilities because of shortcomings in professional work, such as inadequate supervision or inappropriate selection of therapeutic techniques, or poor hiring practices, or failures of audit and inspection..

The crisis of accountability cannot be resolved by a successful search for more efficient means of monitoring or better techniques for insuring compliance. The crisis goes deeper than that. To find

our way out, we must question in practice the fundamental assumptions underlying policy and management in the field. Any approach to assuring safety and quality based on an image of people with developmental disabilities as passive, deficient objects is not just inefficient but counter-productive. Every dollar invested in such activities is worse than wasted because it misdirects attention, time, and money away from the crucial changes in mindset and practice that will make services accountable to the changing realities of the people who rely on them.

	Dominant Pattern	Emerging Pattern
Strategic Challenge	Increasing the availability of professionals to work on changing people with developmental disabilities in bureaucratically managed settings.	Expanding opportunities and assistance for people with developmental disabilities to participate in community life as they choose.
Image of person with a developmental disability	Passive object of professional work. Passive victim of professional neglect.	Author of own life, given opportunity & assistance. Vulnerable participant in conflicts. Potential victim of abuse, neglect, or domination by disrespectful others
Contribution of quality assurance	Assure correct performance of professional work through bureaucratic control.	Promote and disseminate learning from action to increase opportunities for people with developmental disabilities.
Means of assuring safety & quality	Detailed specification of procedures, outcomes, & documentation in legal regulations. External inspection by professional inspectors (perhaps supplemented by panels of 'lay' monitors). Identification of deficiencies in professional work leading to required plans of correction. Administrative sanctions for non-compliance, typically involving threats of loss of funds to serve people or fines.	Strengthen the voice of people with developmental disabilities & their families & friends. Increase capacity to generate new, personalized living arrangements. Develop effective police power to detect, investigate, & prosecute abuse. Enforce contracts to avoid neglect. Negotiate contracts with providers to systematically re-direct service capacity to increase community opportunities & to provide focused assistance. Invest in strengthening learning capacity.

Redefining accountability in terms of the emerging pattern described above is fundamentally a political activity. The many involved stakeholders will need to search together for ways forward. Their search will have to overcome conceptual and emotional barriers, as well as structural and political problems.

Two perspectives can contribute helpfully to the search for accountability. One, which specifies the key to accountability in the emerging pattern, derives from the experience of people with developmental disabilities who have good support. The other originates from the developing field of systems thinking and provides some useful guidance for the process of redesigning approaches to safety and quality.

After naming some of the barriers to thinking deeply about issues of accountability, the remainder of this report briefly explores guidance from systems thinking and develops a perspective on safety and quality from the experience of people with developmental disabilities.

Barriers to thinking deeply about accountability

*Thought Experiment**

At least two states have made substantial efforts to revise their regulations. In both cases, state managers responded to vigorous and sustained complaints that providers were over regulated, and a key goal of the process was to increase local flexibility by streamlining regulations. In both cases, state managers announced willingness to put everything on the table for reconsideration and, if necessary, to work for legislative change or to negotiate with federal funders for changes that would make services more individually responsive. In both cases the work was done by task forces with members representing advocates for people with developmental disabilities, service providers, and involved state agencies. There were ample opportunities for consultation and public comment.

In both cases, the result was as many or more requirements on service providers than existed before the streamlining process began. In both states, providers continue to complain that regulations make it impossible to serve people as effectively and efficiently as they would like. Even those providers who were personally involved in revising the regulations, and strongly argued for including most of the provisions of the revised regulations, join in the complaints.

What accounts for the ironic results of these two efforts at decreasing regulation?

Clichés which block thinking

Each time people are tempted to let go of existing regulatory behavior, at least six clichés recur to tighten their grip on dysfunctional, but familiar, ways. Like all clichés, these reveal a part of the truth while relieving the speaker of the burden of thought and the threat of change.

- *Some providers are just plain bad.* There are persistently abusive or exploitative or neglectful or dishonest people who provide execrable services to people with developmental disabilities and defraud the public. Without adequate police power it would be impossible to rescue their victims. It is easy, though superstitious, to link the need for effective authority with the existing structure of regulations, inspections, and plans of correction. ("Wittgenstein (the person quoted on page 1) can talk about getting

Thought Experiments embody some of the puzzles we have found in our exploration of work to improve the safety of people with developmental disabilities and the quality of the assistance they receive. We don't think these puzzles can be answered unequivocally; at least we can't answer them. We do believe that considering them thoughtfully will help to build the new ways of thinking necessary to taking the next steps toward better lives for people with developmental disabilities.

to the roots of things, but while he philosophizes, people are at the mercy of unscrupulous operators.")

- *Regulations make public agencies accountable.* Bad things will happen to people with developmental disabilities, as they will to people without disabilities. Although many of these incidents will be tragic accidents, some reporters and some politicians project great faith in regulations and oversight as a sufficient means to prevent bad things from ever happening. If something bad does happen, some service provider must have broken a rule and some bureaucrat must have failed to take notice of the infraction. If no rule appears to have been transgressed, someone is responsible for the failure to make a rule. No one relishes the thought of public responsibility for removing any possible protection. ("How would Wittgenstein like to explain to Mike Wallace on 60 *Minutes* that he took away a rule against something somebody has been caught doing?")

- *Inspectors are good people.* Many inspectors are fine, dedicated, capable people. Most all inspectors occupy civil service positions, which vigilant legislative analysts would be happy to delete at the first hint that they are unnecessary. Most inspectors have identified some serious problems and many have made contributions that service providers appreciate. It is hard to talk about redesign without threatening inspector's livelihood and self worth. Their response to this threat is likely to highlight, if not exaggerate, the negative potentials in the system and their ability to overcome them. ("If Wittgenstein had seen what we have seen, he wouldn't be so quick to talk about doing away with the inspectors whose positions we have worked so hard to establish.")

- *The health department and HCFA and Congressperson ____ all say we have to do it.* Over the past twenty five years, the developmental services system has systematically shifted funding away from local and state tax revenues and toward cost sharing with the federal government, chiefly through the medical assistance

program. In many states this splits responsibility for quality assurance between state agencies, and in all states it makes the federal medical assistance bureaucracy a significant actor whose idiom is regulatory process. Fears that change will lead to loss of expanded federal funds, federal audit exceptions, demands for pay-backs, and the shameful end of careers in public administration drives people at all levels to read the minds of the people who regulate the system: "The change seems reasonable to us, but HCFA will never allow it, so lets forget it." Scandal in one part of the country can lead influential members of congress to generalize their staff people's ideas of remedies to the whole system. ("Wittgenstein never had to face a federal look-behind audit.")

- *Without regulations, service providers won't improve.* Regulations have become vehicles for positive aspirations, such as the provision of well coordinated, individualized services. A form of magical thinking inflates the power of regulation and leads people to speak as if changing regulatory language would necessarily deprive people with developmental disabilities of substantive benefits which they now actually enjoy. Thus people recoil from the suggestion that case management requirements be simplified or eliminated when they know that case managers are overcommitted to the point that they have only perfunctory involvement with most of their clients. And people who personally embrace positive commitments say that regulations must remain strong to keep other people in line, even though they are not necessary for them. ("Doesn't Wittgenstein want people with developmental disabilities to have good services and good lives? If rules don't require coordination, there won't be any. Of course, we'd cooperate, but no one else would.")

- *Service providers may complain, but they really like rules.* Current regulations define important boundaries in the existing service system. They offer some leverage to professional advocates, they provide some justification for requests for greater service system funding, and they may set some limits to liability. There are very

significant sunk costs in compliance with existing rules, including hundreds of millions of dollars of capital expenditures on congregate, segregated service settings and years of specialized training for such professional hybrids as the QMRP (Qualified Mental Retardation Professional). Existing rules also give service providers, family members, and politicians reassurance that they are doing the right thing, and proposals to fundamentally change them raise the threat that they have done the wrong thing. Last, but not least, they offer a convenient excuse for avoiding change. ("Wittgenstein is wasting our time; too many people have a stake in the current pattern of regulation to ever change it. He should get real.")

Dealing with these clichés challenges the leadership of people who want to explore new ways to assure safety and quality. The clichés are rooted in a history of cynicism and distrust among the stakeholders in the service system. Cynicism about declared public purposes for services can be justified by repeated legislative failures to back positive intentions with commensurate authority and expenditure, and cynicism about the motives of those who provide or advocate for services can be justified by occasional, but undeniable scandal, and the obvious self-interests of service providers. Distrust can be justified by innumerable examples of screw-ups, sell-outs, betrayals, fiscal improprieties, and outright abuses of people. Unfortunately, cynicism and distrust unleash self-fulfilling dynamics. Structuring the search for greater accountability will require people to test the grounds for cynicism and distrust with new and different kinds of agreements. This demand to build trust among people with long histories of conflict may be enough to keep the field chronically in a crisis of accountability.

New ways of understanding people with disabilities as a barrier to thinking

A deeper barrier to careful reconsideration of the way to safety and quality lies beneath the defenses offered by these clichés. This barrier arises from the novelty of understanding people with developmental disabilities as whole persons, deserving assistance to author their own lives. This kind of novelty creates a conceptual discontinuity –a disorienting break in the terms for problem definition and debate.* To bring this challenging discontinuity into focus, consider this brief historical sketch.

In the US, the search for accountability began in the mid-19th century, as soon as publicly funded institutions did.† From their first annual reports onward, the social reformers who founded services sought ways to...

...justify increasing public expenditure on the work they were convinced was right

...design physical environments to support their therapeutic aims

...hire, train, organize, schedule, and supervise the assistants and attendants who would carry out their regimen correctly and humanely

...deal with their failures

These concerns, and an underlying view of people with developmental disabilities, have largely defined the terms of the search for accountability until now. The function of accountability mechanisms, from 19th century annual reports to modern certification procedures, is to justify professional work to legislative bodies and thus expand professional scope through increased expenditure and increased authority. Though the forms of justification vary with changing social climates and fluctuating levels of public concern, the position of people with developmental disabilities remains constant. Whether the administrator's intent is to educate them or

* See Margolis, H. (1987). *Patterns, thinking, and cognition: A theory of judgment.* Chicago: University of Chicago Press for an interesting discussion of the barrier of novelty to accurate perception and informed judgment.

† See Ferguson, P. (1988). ***Abandoned to their fate: A history of social policy and practice toward severely retarded people in America: 1820-1920.*** Doctoral dissertation, Syracuse University, Syracuse, N.Y. and Graney, B. (1979). ***Hervey Backus Wilbur and the evolution of policies and practices toward mentally retarded people.*** Doctoral dissertation, Syracuse University, Syracuse, N.Y. Ferguson's discussion of the invention of chronicity as a means of dealing with persistent professional failure is especially enlightening.

to segregate and control them at minimal state expense, people with developmental disabilities are viewed and treated as other than, different from, and less than their keepers and therapists. Whether seen as dangerous, pitiable, trainable, or victimized, the role of people with developmental disabilities is to follow the prescriptions of those in authority over them; that is, anyone apparently less disabled then they are, who claims the authority to tell them what to do.

Justifications for this treatment vary depending on social climate. In times when the public mission of services emphasizes the discipline and control of the unruly poor, keepers assert that people with developmental disabilities must be obedient because they are a burden on public charity. The best interests of the state are served when services discharge this burden at minimum cost and in a way that discourages others from adding to the public charge by seeking assistance. In times when the public mission of services emphasizes the therapeutic, professionals say that people with developmental disabilities must obey for their own good. They, and their families, will do better when they follow the directions of professionals who know better. State costs of therapeutic services will be minimized when clients accept their duty to follow the prescribed regimen that will make them less costly as they acquire the skills to become independent. Whichever set of terms is most common at a given time, the other set is close by. Many keepers also assert the therapeutic benefits of their discipline and many therapists also acknowledge that both their clients and the costs of service would run amok without firm controls.

Oddly, the last thirty years emphasis on the rights of people with developmental disabilities seem to have had little impact on the terms of the search for accountability. Perhaps this is because both litigation and legislation have largely accepted the common assumptions of the field. Advocates publicly diagnosed horrible institutional conditions as caused by the triumph of custodial over developmental impulses. The remedy thus becomes obvious: replace keepers with many disciplined therapists whose work is orchestrated by an individual habilitation plan, and replace cheap and squalid warehouses with much smaller and more dignified therapeutic environments, whose increased costs will be reclaimed by the cost reducing performance of newly skilled clients. Advo-

cates publicly diagnosed denial of education as lack of access to professionally composed and implemented individual education plans, and the due process machinery necessary to insure the proper exercise of professional judgment. While significant benefits have come to many people with developmental disabilities through the success of these efforts, their very success reinforces the position of people with developmental disabilities as the objects of professional work. One can be accorded one's full rights to due process and enjoy all of the benefits of a team planned IHP while asleep or comatose; this is both the strength and the limitation of much current work for people's rights.

Even the principle of normalization (and its partial successor, social role valorization), arguably the most carefully elaborated theory of service reform, presents people as victims of wounding experiences which are mitigated by professionally directed efforts to enhance the image and the personal competence of people with developmental disabilities. The valuable lessons of this theory have motivated and guided many constructive service reforms. But, within the theory, people with disabilities remain, for the most part, in passive roles, either benefiting from correct treatment or suffering from devaluing treatment at the hands of professionals.

The quiet revolutionaries who daily find their way through the economic and civic life of their communities and come home to unlock their own front doors daily overturn the logic of the past 160 years. This is particularly true when they rely on a personal assistant to turn their key or a co-worker to guide them in mastering a new task.

Story has it that the authorities who disapproved of Galileo's ideas about the movements of the planets refused to look through his telescope in order to see for themselves. They already knew what wasn't there.

People with developmental disabilities can ill afford our collective failure to look carefully and think deeply about the emerging experiences of people with developmental disabilities who have new opportunities and reasonable support. But such a look will fundamentally challenge our habits of understanding and action. Inability to assimilate this discontinuity may be enough to keep the field in a chronic crisis of accountability.

Effective interdependence as an emerging perspective on the search for accountability

Growing differences separate the everyday life experiences of people with developmental disabilities. Some people once institutionalized as hopelessly incompetent now have the assistance they need to participate in everyday life, and deal with life's ups and downs; others remain buried in institutions, large and small. Some people once hidden as shameful and assumed to be socially unacceptable now count ordinary citizens among their neighbors, school and work mates, and friends; many others remain isolated. Some people professionally diagnosed as incapable of meaningful communication and choice now make their individual and collective voices heard; others remain silenced.

These palpable differences in life experience can not be explained by differences in ascribed level of disability, though this mistaken common sense explanation hangs on persistently. And, while competent technical help of the sort provided by experts in instruction, communication, mobility, and personal problem solving clearly matters, professional work does not, by itself, produce these differences. These result from different kinds of relationships among people with disabilities, their families and friends, their service providers, and their fellow citizens –relationships built on the realization of common humanity.

Realization that people with developmental disabilities have the same sorts of needs and aspirations as anyone else usually leads to recognition that they are systematically disadvantaged by socially devaluing practices which are so common that they are almost automatic. When this recognition engenders commitment to join with disabled people in order to resist discrimination and work for justice in everyday settings, effective interdependence grows.

Working for justice in everyday settings only occasionally involves the machinery of formal complaints or the drama of direct action. Confrontations are often indirect, even gentle –as when a person with a developmental disability and her assistant arrive to look at an apartment offered by a landlord who begins the conversation by speaking to the assistant about the disabled person and ends up, effectively redirected, sharing a joke with both of them, or

when an employer is encouraged to figure out a job adaptation by a job coaches' question, or when a probate judge faces a man who has, at his own initiation and with his residential support worker as scribe, "Written down here twenty-seven good reasons why I should now make my own decisions and my guardian should be fired. She did a good job of being guardian and I like her, but I don't need her and I don't want her as the boss of me."

When forced into dependency or isolation, people with developmental disabilities wither into the stunted social roles which reflect common prejudices. They become no more than clients to be processed, passed over, or pitied. Effective interdependence differs importantly from both dependency and isolated independence. A woman with cerebral palsy spells out the difference this way, "Dependency: just doing what I'm told –goes noplace, no fun! Isolation: having to do it alone –can't do much. Interdependence: figuring out what we can do together –nobody can say how far we can go!"

The qualities of effective interdependence

An interdependent relationship incorporates at least two viewpoints. The discussion here will mainly explore the qualities of effective interdependence from the point of view of those who offer assistance. This is because we think that the legitimate purpose of safety and quality assurance mechanisms is to guide the contribution staff make to these essential relationships and not to directly regulate the behavior of people with developmental disabilities.

Over and over again, people providing the assistance people with developmental disabilities need to open up new opportunities return to the same themes as they discuss their work.

- A job coach, "Lots of people with developmental disabilities want to work so they can enjoy the same rewards for being productive that I do. They deserve a fair chance to work and learn from their successes and their mistakes. But the deck is stacked against them: employers haven't had the chance to consider hiring them and lots of employers are afraid because they don't know people, only stereotypes; people's wishes and

dreams have been ignored, or even punished, by service providers, so their self confidence has taken a beating; people haven't had much chance to learn real job skills or figure out how to get along with the many kinds of people they meet at work; and people's parents are scared that they'll be hurt and that their benefits will get screwed up. That's where I come in. My job is to help people figure out the way through all those barriers."

- A supported living worker, "All she wants is to be in control of her own life and to keep the apartment she loves. That sounds simple, but about a million problems keep coming up to threaten her; she has so little to fall back on that little problems can get very big. It's up to me to keep the problems as little as possible. Even though she can now manage most all the everyday things for herself, I'm in it with her for the long haul as far as the out of the everyday problems are concerned."

- A case manager, "They thought hard about their decision to have a child. We talked and talked about it and finally, between them and the grandparents and our agency, we figured out a way to provide just the support they needed. Now someone (we think a nurse at the public health clinic who gave the baby a shot) has called protective services. We're sure there is no question of neglect, but we've got some educating to do -and we have to be sure that everybody stays calm and keeps on track."

- A psychologist, "In the institution he seems to have learned that the only way to have any control was to be really disruptive and angry; to kick and hit and throw things. We have to figure out how to show him that we are on his side; that we want to know his preferences and that we'll do our best to help him get them. Until we earn his trust, things will be pretty rocky for all of us."

These relationships share several important characteristics. Staff people...

...demonstrate respect and active concern for the person's interests and desires by making them the focus of their work.

...appreciate the ways a person's disability and a person's unique history affect everyday life and focus on offering or arranging practical assistance to deal with whatever problems arise.

...recognize barriers in discriminatory treatment perpetuated by service system procedures and community member's habits and put themselves on the person's side in confronting these problems.

...know that a person may well need some assistance for extended periods of time.

These relationships seem far more collaborative than therapeutic; staff skills matter, but in the context of a shared goal. As one professionally trained staff person put it, "Before, in the activity center, I did special education on the clients. Special education was what I was there for: my relationships with people were a way to make my skills work better. Now, as a job coach, I use my instructional skills all the time, sometimes without even thinking about it. But my skills aren't the reason I'm there. My agreements with people who want jobs are the reason I'm there. No more clients; just people who need my help to find and keep good jobs."

People with developmental disabilities are no more likely than anyone else in our culture to be skilled and trustworthy in collaboration. People with developmental disabilities are just as likely as anyone else to get into jams and act in self defeating ways. People with developmental disabilities are just as likely as anyone else to have irritating habits or to act hurtfully toward people who matter to them. And working hard for something important doesn't always mean getting it. So staff people are likely to sustain some hurts in these relationships. And, being people, staff may inflict some hurts as well. To seek interdependent relationships is to choose vulnerability, not just to the person with a developmental disability, but to community employers and co-workers, extended family members, landlords and neighbors. It is also to choose vulnerability to one's own human weaknesses.* Good skills at repairing relationships are even more important than skills at making relationships in the first place.

* For a helpful discussion of the importance of such vulnerability in the exercise of leadership, see DePree, M. (1989). *Leadership is an art.* New York: Dell.

Effective interdependence defies efforts to set detailed, clear boundaries around job descriptions or service specifications ahead of time. Indeed, the focus of effective interdependence is on re-negotiating boundaries in order to make change, and how to adapt assistance to changing circumstances.

At the most mundane level, a supported living worker needs the discretion to decide how adapt the amount of direct help she provides with household chores to the changing circumstances of the person she assists. Someone who is feeling blue over the break up of a relationship might need some extra help with cleaning up and cooking for a couple of weeks. Someone recovering from a bout of pneumonia might need a daily reminder to take prescribed antibiotics, "right down to the last pill, even if you feel better." It would be absurdly expensive to require a team to meet and debate formal amendments to an individual service plan or consider a referral to a worker with health care in her job description in order to make such simple accommodations (and it would be gratuitous to mention these foolish inflations of transaction costs if they did not both reflect actual practice in agencies we have visited).

Uncertainties abound which cannot be sensibly regulated from a manual. Do Mary's complaints of sleepiness call for another visit to the neurologist to re-evaluate her seizure medication or should we wait six weeks for her regular appointment? Mary says she doesn't really know what to do and asks for advice. The last time we went for an extra appointment, the doctor gave Mary a lecture about wasting his time. Maybe we should help her look for another doctor? Steve's neighbors have called our agency again complaining about how loudly he plays his music. Should we talk to him again or should we encourage the neighbors to complain directly to him. It might be the beginning of a more neighborly relationship, or, it could be round one of a big fight.

Progress requires many adjustments too. A job coach who successfully assists a worker with a developmental disability to recruit the help he needs from his supervisor and his co-workers needs the flexibility to shift her involvement based on changing circumstances. A two week vacation by a key supervisor can deeply disrupt the almost invisible web of support essential to competent performance. Success may encourage a person's desire for a better, more challenging job. A short lay-off may throw residential sup-

port workers into confusion. Unless assistants keep in touch with what's happening and take responsibility to move in and out where, when, and as necessary, people lose jobs and miss opportunities.

Of course, discretion requires support. Small adjustments can add up to big changes in resource allocations. And only a person with delusions of omnipotence would want to make these judgments alone. Effective team work, focused on real world problems, done when problem situations are occurring and usually informally, provides one key support. Occasional time out for reflection on the issues emerging from the day to day work provides another.

Paradoxically, effective interdependence seems to call for strong agency leadership. Decisions that matter to the quality of individual and community life and to the maintenance of positive relationships must be made, usually under pressure of time, uncertainty, and conflicting ideas and values.* Agencies with a high proportion of staff in effectively interdependent relationships seem to have several ways to structure their decision making:

- Small groups of involved staff are expected to make decisions which commit agency resources and represent agency positions in a timely way and in consultation with the involved person with a developmental disability.
- These groups expect their decisions to be judged by their fit to agency values, including an explicit value on fitting responses to personal knowledge of the history of the person with a developmental disability and doing "whatever it takes" to assist the person to live with safety and in a way that protects and expands the person's opportunities to participate in community life.
- People are available to consult and assist the problem solving process if the responsible group feels stuck.
- A group that cannot reach timely agreement is expected to refer the decision to a person who has the clear authority to decide and who is seen to hold personal responsibility for agency values.

* This point is made in somewhat different terms in Hirschorn, L. (1993). Hierarchy versus bureaucracy: The case of a nuclear reactor. In K. Roberts (Ed.), *New Challenges to understanding organizations*. New York: Macmillan, pp. 137-149.

When these structures are weak or absent, the agency contains a strong attractor for bureaucratic procedures which serve the function of defending staff against making decisions.

It's impossible to listen carefully to direct service workers who are effective assistants to people with developmental disabilities without recognizing that their work has a very high knowledge content. Unless direct service workers decode everyday situations for potential problems and potential opportunities and then find practical ways to act on what they see, many people with developmental disabilities will be stuck without a chance. Missed opportunities and unnecessarily complex problems result when direct service staff feel like their job requires them to check their brains at the door.

The dominant pattern ignores the central place of knowledge in direct service work. Existing regulations situate direct service workers as instruments of professional judgment. From this point of view, ideal direct service workers play the role of arms and legs, remotely controlled by professional brains through such media as program plans, task analyses, policies, and procedures. Blanket rules are supposed to govern behavior. "Always refer a medical question to the physician" or "always let people experience the natural consequences of their behavior." This kind of rule following pre-empts important questions about Mary and Steve and their particular present situations, and thus reduced the amount of imagination and thought that they put into their relationship. The costs of this loss of intelligence are large, but unfortunately easily hidden. It is in people's identities, and in their particular, present situations that opportunities for real personal and social change lie.

To define boundaries for the work of assisting people with developmental disabilities, it makes more sense to describe the kind of relationships and the types of problem situations entailed in providing good support than to try to specify job descriptions and behavior. Such statements of obligation offer direction and provide

a framework for learning through day to day problem solving. The following example is taken from a statement by a group of supported living agency leaders.

For example

Understanding the obligations of supported living*

Supported living workers recognize that people with developmental disabilities need committed, capable allies if they are going to overcome the barriers imposed by widespread prejudice and discrimination. Becoming someone's ally doesn't necessarily mean becoming their close friend or endorsing everything they do or want. It means being willing to be involved in a constructive way in helping a person discover and more toward a desirable personal future.

One way to clarify this essential relationship is to say what obligations the providers of supportive living accept in relation to the person they assist.

Obligations to the person

We acknowledge that in order to assist you effectively we must earn your trust and the distinction of being your ally by...

...treating you with respect and listening carefully to you so that we can keep getting to know you better

... learning with you about your interests and preferences and identifying the kind of home that will offer you a safe, decent base for your participation in community life

...learning with you about the kind, amount, and style of assistance you need to live successfully in your home and your community

...working with you, and your family and friends, to establish the home life you desire and the assistance you need

...recognizing the social, financial, and personal barriers to the kind of home life you want and assisting you to work to overcome them

...understanding the vulnerabilities to your well being that result from your disability and your personal history and carefully negotiating safeguards with you that balance risk and safety in a responsible way

...being flexible and creative with all the resources available to us to respond as your interests, preferences, and needs change

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* From O'Brien, J. (1993). *Supported living: What's the difference?* Syracuse, NY: Center on Human Policy. This way of thinking about obligations came from reading DePree, M. (1992). *Leadership jazz.* New York: Doubleday Currency.

...keeping responsibilities clear so that, in every area in which we work together, you and we know what you will contribute, what your family and friends will contribute, and what assistance and support we will contribute

...minimizing our intrusion in your life by periodically checking to make sure we are not doing unnecessary things or doing necessary things in intrusive ways

...sticking with you in difficult times

...learning from our mistakes

...following through on our commitments to you and not making promises to you that we can't keep.

We recognize that social, legal, and service developments open many new possibilities for people with developmental disabilities and we accept responsibility to...

... provide you with information

...invite and encourage you to try new experiences

...invite and encourage you to widen your circle of friends and contacts

...hold high expectations for the quality of your life as a full citizen and community member

...stretch our own awareness of possibilities by actively seeking contacts with people involved in building up our communities and with people who are developing more effective and practical ways to assist people with disabilities

We know that you could find yourself in conflict with others: neighbors, landlords, other service providers, or the law. In these conflicts we recognize our responsibility...

...to be on your side, in the sense that we will assist you to achieve the best resolution of the conflict possible in the circumstances

...to assist you to understand the conflict and to consider alternatives for its resolution

...to assist other parties to the conflict to understand your position

...to consider adjusting kind or extent of assistance we offer you if that adjustment will help to achieve a satisfactory resolution of the conflict

We realize that you may disagree with us or be dissatisfied with our assistance to you and we accept responsibility to...

...negotiate openly with you in search of mutually satisfying outcomes

...try new ways to assist you and then check to see if the new approach has good results

...work hard to understand your communications about the adequacy and acceptability of assistance, especially when you can express yourself better through your behavior than in words

...assist you to explore other sources of assistance if you want to do that

We recognize that you might find close friends among our workers and, while we neither expect or require this kind of relationship, we gladly accept the potential difficulties that this might involve.

Obligations to the person's friends and family

We acknowledge your importance to the person we assist. We want to invite and encourage your active support for a positive future for the person we assist; we do not in any way seek to replace you in the person's life.

We recognize that you may disagree with us or be dissatisfied with the assistance we provide, we accept responsibility to...

...respond to your concerns about the person's safety and well being

...negotiate openly with you in search of mutually satisfying outcomes

We realize that you and the person we assist may have different, perhaps even conflicting, ideas about what is possible and desirable for the person; in the event of these differences we agree...

...to uphold the importance of mutually respectful relationships among family members

...to assist you to negotiate a satisfactory resolution to the conflict, if our help is acceptable to you and to the person we assist

...if the conflict is serious and you cannot resolve it, we will maintain respectful contact with all parties but honor the choice of the person we assist.

These obligations make plain an uncomfortable fact at the heart of supported living: to assist people with developmental disabilities in this way is to become vulnerable to them, to their families, and to their communities. Our success depends more on inviting and assisting people with disabilities and community members to do what we cannot do: create satisfying lives and fulfilling community relationships.

Safety and effective interdependence

Thought Experiment

Regulations require that services be developed and delivered based on individual need. Inspectors sometimes produce findings that a program is not adequately meeting the individual needs of people in settings that they visit briefly, as strangers. They typically base their conclusions on information gathered during an annual review in which they read records, observe program activity, and, sometimes, briefly interview people with developmental disabilities.

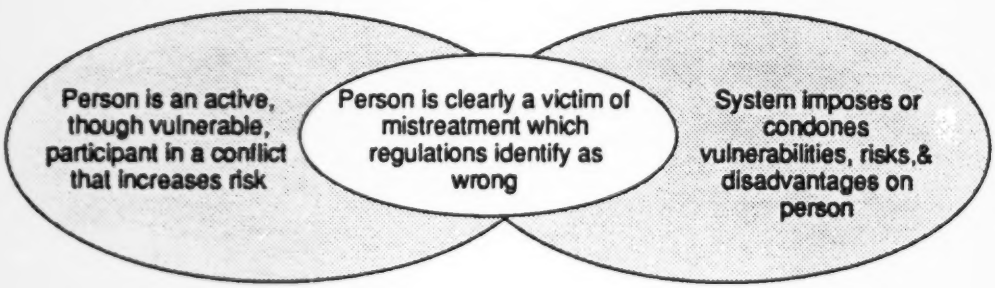
Under what conditions can outsiders make such a judgment with greater confidence than those staff who spend every day with people?

Under what conditions is it reasonable to decide that program staff are likely to have better knowledge of the people that they assist than inspectors are likely to have, thus rendering inspector's judgments redundant in the event of agreement with staff or probably mistaken in the event of disagreement?

Would you feel secure and comfortable if you lived in a place where inspectors who have never met you before and may never see you again can typically know much more about your individual needs and preferences than the people you rely on every day know?

Most current attempts to assure safety and quality are either largely irrelevant, because they ignore most of the circumstances that contribute to the vulnerability of people with developmental disabilities, or misdirected, because they emphasize impersonal procedures over the kind of interpersonal relationships that offer vulnerable people the best chance of being safe.

Present regulations focus on the black and white area depicted on the diagram below. They concentrate on forbidding mistreatment in situations where the person with a developmental disability is


Person is an active, though vulnerable, participant in a conflict that increases risk
Person is clearly a victim of mistreatment which regulations identify as wrong
System imposes or condones vulnerabilities, risks,& disadvantages on person

victimized. However, people with developmental disabilities face an increasing number of gray situations in which they are vulnerable.

As the right side of the diagram suggests, many people with developmental disabilities find themselves in situations that increase their vulnerability but are condoned, or even imposed by the service system's policies and regulations. Increasing numbers of people with developmental disabilities have no alternative to remaining in their parent's homes and on waiting lists for assistance with daytime opportunities or living arrangements. Other people with developmental disabilities live against their will in miserable conditions in nursing homes which display banners proclaiming "Congratulations to Our Staff on 100% Compliance In Our Last Inspection." Curiously, these imposed disadvantages could be dealt with by system policies. Their invisibility stabilizes existing allocations of funds, status, and power.

As the left side of the diagram suggests, a person with a developmental disability can play an active role in increasing their own risk.* As people move away from the danger and oppression of total institutions, many more of these threats will arise. Such conflicts include, for example, a pattern of stealing from community members, repeated attacks on other group home residents, mutually upsetting arguments with staff, or very difficult behavior which the service providers involved believe arises more from their failure to find proper means of communication than from willful dangerousness.

Legally competent people with developmental disabilities also make apparently risky choices about people to associate with, sexual expression, use of money, diet, weight, and compliance with medical advice. While risky and undesirable, most of these latter choices fall well within the personal experience of many of the staff and family members involved, e.g. some case managers' physicians have told them that they are obese, and, in their private lives, some service providers have chosen investments, activities, and relationships which others have disapproved of as unwise or even exploitative or dangerous. These risky choices fall in the gray zone because the people involved see clear trade-offs between the consequences of risky choices and the consequences of intervention to forestall them.

* Many of our ideas in this section came from discussions with service providers, guardians, and family members in five Wisconsin counties and on our reflections on these discussion with Marcie Brost, who shared thje work of interviewing.

People with developmental disabilities often come into these conflicts as vulnerable participants. They have less helpful experience, or fewer social resources, or less physical or cognitive ability than staff members or family members do. Moreover, virtually all of these threats occur to people whose lives are both improving and remaining, or becoming, dangerous in some particular way.

A person who is an active participant in a conflict that increases vulnerability calls on the cooperative problem solving and negotiation skills of the people they rely on for help. People need to come together, share their perceptions and beliefs, deal with conflicts, and figure out how to take the next steps. Conflicts arise between the person and those who want to help, between the person and other agencies (such as the social security administration, the police, and the courts) and between the person and other community members. Most of these conflicts are not single episodes but continuing situations; so they test people's willingness to stick with the person.

These complex patterns of problem solving typically must be sustained in highly uncertain, emotionally charged circumstances. The necessary judgments are far too complex to be codified in simple rules, though aids to decision making like the one below can capture important aspects of the problem solving process. Guides like the one on the next page,* which arise from and are modified by experience, can serve somewhat the same function as emergency checklists serve for the pilots of an airplane in trouble. They can insure that important questions don't get missed when people are anxious and liable to flee from the frightening situation.

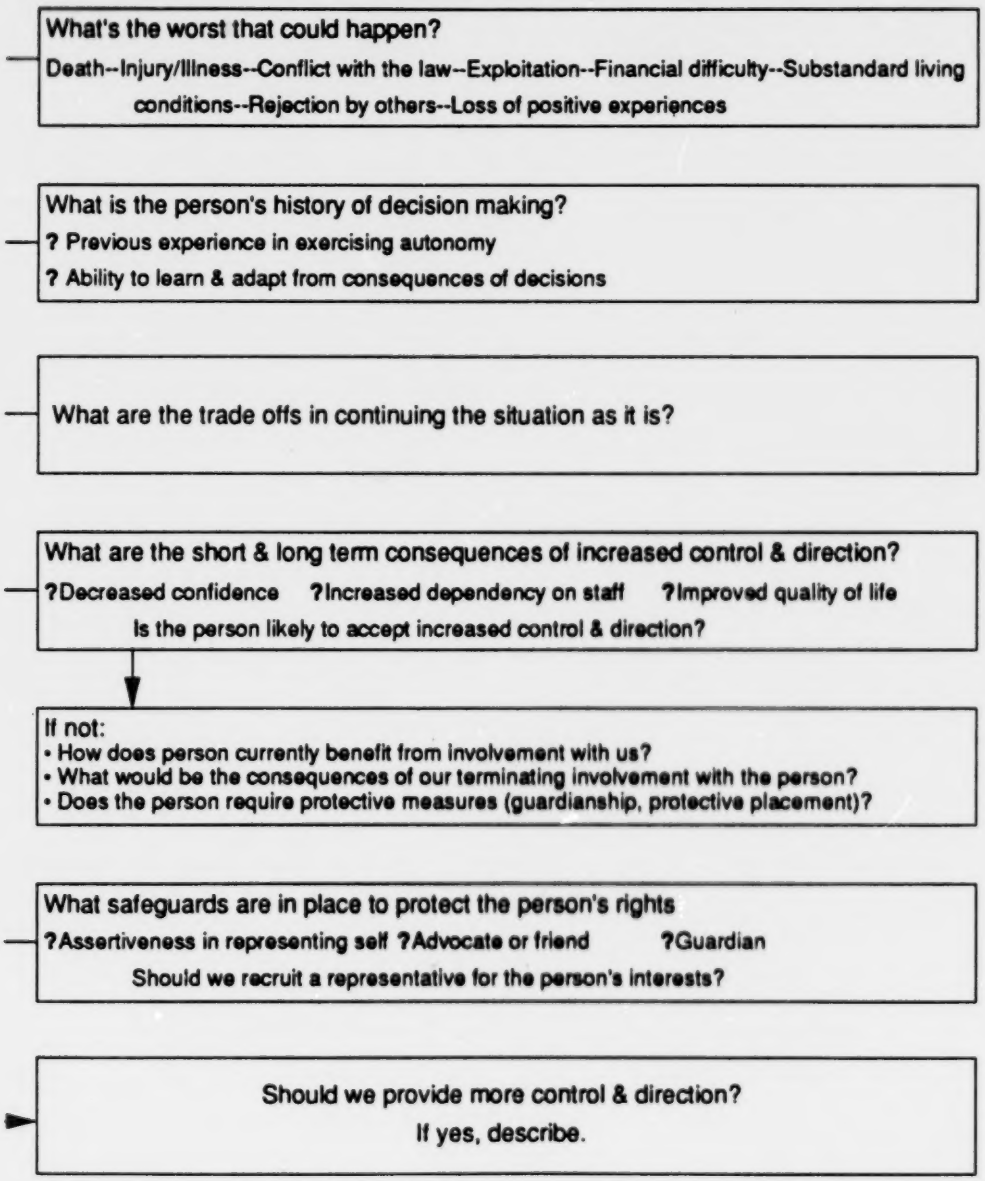
What matters most to people's safety is the extent and quality of their relationships. People are safer the more others care enough about their safety and well being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships. But most current policies and practices ignore these vital relationship issues, and most service dollars are spent on congregating people with developmental disabilities in settings which segregate

* Adapted from materials used by staff at Options in Community Living, Madison, WI.

them. By suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people's most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt.

For Example

Considerations When A Person's Decisions Put the Person At Risk


What's the worst that could happen?
Death--Injury/Illness--Conflict with the law--Exploitation--Financial difficulty--Substandard living conditions--Rejection by others--Loss of positive experiences
What is the person's history of decision making?
? Previous experience in exercising autonomy
? Ability to learn & adapt from consequences of decisions
What are the trade offs in continuing the situation as it is?
What are the short & long term consequences of increased control & direction?
?Decreased confidence ?Increased dependency on staff ?Improved quality of life
Is the person likely to accept increased control & direction?
If not:
• How does person currently benefit from involvement with us?
• What would be the consequences of our terminating involvement with the person?
• Does the person require protective measures (guardianship, protective placement)?
What safeguards are in place to protect the person's rights
?Assertiveness in representing self ?Advocate or friend ?Guardian
Should we recruit a representative for the person's interests?
Should we provide more control & direction?
If yes, describe.

Integrity as a central virtue in effective interdependence

Effective interdependence depends on the social learning that results when people with developmental disabilities and their friends join with their paid assistants to create new opportunities in everyday life. A hand lettered message on the back of a person's wheelchair signals the importance, and the ordinariness, of this mission. The sign said, "To boldly go... where everybody else has already been."

The personal learning and organizational realignment necessary to support this mission depends centrally on the civic virtue of integrity. This Chinese ideogram, has been translated as "integrity."* It includes an open eye, an open heart, and arms and legs, signifying action.

This symbol expresses the core of effective interdependence: aligning action with increasing consciousness and openness to the habits and lessons of the heart. From this perspective, integrity is a physically embodied virtue: it arises from action in relationships rather than being assumed in response to rules.

Without integrity among those who provide necessary assistance, people with developmental disabilities can only be as safe as obedience to external authority can make them. Without integrity among those who provide necessary assistance, the gifts and contributions of people with developmental disabilities will remain hidden and they will never enjoy the freedom of responsible citizenship.

* This ideogram forms the central character, *Te*, in the earliest extant manuscript of the *Tao Te Ching*. See Beebe, J. (1992). *Integrity in depth.* College Station, Tx: Texas A&M University Press. pp. xii-xiii.

Threats to integrity from the dominant pattern of quality assurance

> *"Don't you think you'd be safer down on the ground? [Alice asked]... That wall is so very narrow!"*
>
> *Humpty Dumpty growled out. "Of course I don't think so! Why, if ever I did fall off–which there's no chance of– but if I did– " Here he pursed his lips and looked so solemn and grand that Alice could hardly help laughing.... "If I did fall," he went on, "the King has promised me –with his very own mouth– to–to*
>
> *"To send all his horses and all his men," Alice interrupted...*
>
> *"Yes, all his horses and all his men." Humpty Dumpty went on. They'd pick me up again in a minute, they would!"*[*]

David Bohm wryly defines insanity as doing the same thing over and over again and expecting by this to create significantly different results.[†] By this definition, the system of services to people with developmental disabilities slips deeper into insanity everytime managers implement another superficial rearrangement of the quality assurance system.

Thought Experiment

External review of one state's written inspection reports and plans of correction for several residential providers funded as ICFs-MR over a three year period revealed the following pattern. Each year inspection reports document what inspectors identify as serious violations of health, safety, and human rights provisions of the regulations. The facility is threatened with loss of certification and thus of funding. The facility negotiates for time to make a plan of correction to deal with the issues identified and the threat to certification is withdrawn. The next year's inspection documents what inspectors identify as serious violations of health, safety, and human rights provisions of the regulations; these are somewhat different in detail from the deficiencies identified in the previous report. The facility is again threatened with loss of certification and again negotiates successfully for time to plan to correct deficiencies. The next year's inspection report documents what inspectors identify as serious violations of

[*] Carroll, L. (1960 [1896]). *Through the looking glass and what Alice found there.* In M Gardner, ed. *The Annotated Alice.* New York, Bramhall House, pp.. 263-265.

[†] Bohm, D. *Dialogue.* Palo Alto, CA: p.

the health, safety, and human rights provisions of the regulations; these are somewhat different in detail from the deficiencies identified in the previous reports.

How could this pattern best be explained to a person with a developmental disability who lives in one of these facilities?

What has been the public's return on the tax dollars invested in these inspections over this three year period?

Could the endurance of this pattern be broken by...

...tougher regulations with much stronger sanctions?

...more or better trained inspectors?

...inspectors to inspect the work of the inspectors?

...more investment in training and technical assistance for operators of ICFs-MR?

The system seems compelled to repeat a simple, escalating pattern:

Step	Example
1. Discover something bad happening to people with developmental disabilities, often stimulated by an expose.	• People in institutions have no meaningful activity; they simply mill around in large groups or lie in cribs.
2. Define an answer to the apparent problem in the form of a bureaucratic requirement to provide a professional solution.	• Documented active treatment, prescribed by a multidisciplinary team
3. Inspect for compliance with requirements and require corrections for non-compliant situations.	• Threats to funding for non-compliance. • Training and technical assistance to insure compliance.
4. Rates of compliance problems become standards for system performance. The greater the amount of non-compliance the stronger the justification for increased effort to force compliance.	• Sanctions (threats, perhaps fines or loss of income) for managers found out of compliance. • Congratulations and promotions for managers who maintain "100% active treatment."
5. Identify next problem and repeat.	

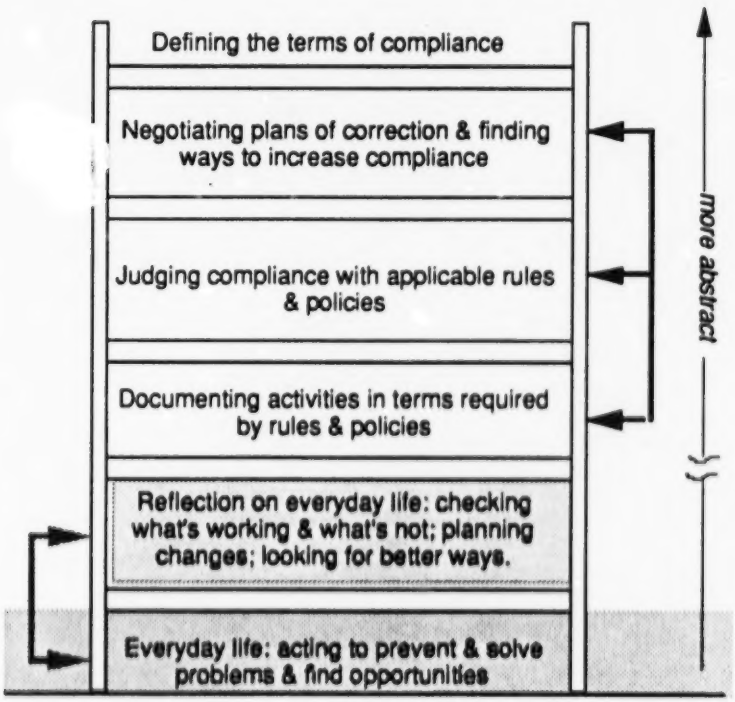
At least five things are worth noticing about this pattern. First, it makes sense in that it responds to obviously serious problems. Second, it makes sense in terms of commonly held notions of public management: higher authorities define the performance they want in the form of detailed specifications, provide incentives (mostly penalties for non-performance), inspect to insure that they get it, and require corrections when they don't get it.

Third, the solutions embodied in the requirements are essentially the simple negative of the observed problem and the good effects of multiple imposed solutions are assumed to be additive (if one is good, two is better, three is even better). Problem: people are idle and untutored; solution: they should be actively treated. Problem: people have been (or logically could be) exploited by people with criminal records; solution: check the fingerprints of anyone hired. Problem: staff sometimes appear to exercise poor judgment; solution: 30 hours of required training for anyone hired. Multiple requirements, the rule makers assume, will not conflict and adding more requirements will not hinder performance. This simple, linear approach has the appeal of the plain declarative sentence.

Fourth, the rules assume that the system and its service providers have the capacity to implement them, or that they can relatively easily acquire the necessary capacities. This sequence admits no significant uncertainties, no significant time to learn to do what is required, and little probability that the requirements themselves will be fundamentally altered.

Fifth, each step in the pattern climbs one more step up the ladder of abstraction depicted on the following page. On the ground are particular people with developmental disabilities and those who assist them to get on with the flow of their everyday life. On the first rung, these people stop to check on what they are doing and, perhaps, invest some time in opportunity finding and problem solving. On this rung they may ask for some help in the form of process consultation or chances to learn new skills or use new equipment or find ways into new opportunities. The second, and subsequent rungs of this ladder of abstraction are imposed by the current system of regulation. On the second rung, people are involved in making descriptions of their activities in terms given by applicable policies and regulations. On this rung, people strive to

prepare documents to standard: the inspector's goad, "If it isn't documented, it wasn't done," rules here. On the third rung, inspectors categorize the evidence available to them from reviewing documentation and brief observations and interviews in the terms given by policies, regulations, and interpretive guidelines. On this rung, judgments of compliance or non-compliance are made. On the fourth rung, administrators and inspectors negotiate about the consequences of the inspector's judgments about compliance. On this rung, plans of correction are agreed and technical assistance requests are formulated and answered. On the fifth rung, experts compete to influence authorities about the definition of the categories and the information that will signal compliance and about the effects of different kinds of sanctions.


Defining the terms of compliance
Negotiating plans of correction & finding ways to increase compliance
Judging compliance with applicable rules & policies
Documenting activities in terms required by rules & policies
Reflection on everyday life: checking what's working & what's not; planning changes; looking for better ways.
Everyday life: acting to prevent & solve problems & find opportunities
more abstract

People live and seek opportunities and solve day to day problems on the ground and on the first rung of the ladder of abstraction. The issues at this level often demand creativity, but they are made of the facts and feelings and understandings of everyday life: Joe's personal assistant is sick again; who will fill in so he can get to work on time? Is a problem developing with the scheduled assis-

tant? Do we need to re-work the schedule? When one climbs to the second rung and above, the world begins to look very different: Is Joe's program plan finished and signed? Has his dentist sent back his annual report? Have his hours of assistance been entered under the proper categories? Have we documented progress on last year's objectives? Administrators, inspectors, analysts, and many professional advocates spend most of their time on the third rung or higher; no wonder so many quality improvement projects focus on improving the quality of paperwork.

A colleague who is both the mother of a man with a developmental disability and a senior program staff member captures the difference that these differences in perspective make in this way, "I live life with my son and then I go to work and read and listen to debates about regulatory reform and quality assurance indicators. I think that, as a mom, I am in an entirely different movie from the one the people talking about quality assurance are watching. It's almost impossible to see the connection between what we are living and what they are talking about."

To understand the consequences of this structure over time, consider the two problem solving loops depicted on the ladder diagram.* The bottom problem solving loop concerns what needs doing everyday to open up new opportunities and to deal with everyday problems; it is here that people can work on the more fundamental causes of better lives for people with developmental disabilities. The top problem solving loop concerns what to do to maintain compliance and the flow of funds to the agency; here the effect on life for people with developmental disabilities is at best indirect. Over time the top loop will tend to dominate the bottom loop: an increasing amount of activity will go toward running up the score on the abstract scoreboard of paperwork, cost reports, and compliance. Less work will be directed at defining and solving the everyday problems that have the potential to improve quality of life.

This domination of the everyday by the abstract largely happens outside conscious awareness because people who are involved in the work of compliance learn to see the abstractions they pursue as

* This is a simple version of a common self defeating pattern in human systems which some systems thinkers have called "shifting the burden." See Senge, P. (1990). *The fifth discipline.* New York: Doubleday

more real than the concrete problem solving that engages people. They do not choose to ignore activity at the bottom rung of the ladder, it is simply invisible or irrelevant to them. Philosopher A.N. Whitehead named this perceptual effect of attention "the fallacy of misplaced concreteness."* People suffer from this fallacy when they act as if writing an individual program plan in the correct form was in itself sufficient to cause improvement in everyday life. This leads the people who stand on higher rungs of the ladder of abstraction to discount the hard every day work of assisting people in favor of the easier task of manipulating symbols on staffing compliments, schedules, plans, budgets, and professional records. This discounting is made much easier by the common dismissal and ignorance of the work of caring as "just women's work."

Paradoxically, regulations worked most effectively for people with developmental disabilities early in the regulatory life-cycle, when inspectors had relatively little sophistication and when the basic concepts, processes, and penalties were relatively poorly defined. At this point, most settings for people with disabilities lacked direction and focus. The staff in them were frozen, without rationale for their work. Those who wanted change could find little leverage. The prospect of new money, new ideas, and a new reason for working had the positive effect of unfreezing settings and making space for change to happen. As regulatory efforts became more effective, compliance activities began to absorb available flexibility, refreezing the system around professional activity. Positive effects decreased to the point where regulation is now counterproductive: more investment in inspector training, refinement of definitions, tools, and incentives will result in worse performance.

The leverage in this situation lies in understanding this paradox. By greatly weakening regulatory activity while simultaneously raising attention to the social learning made possible by working with integrity, over time, on everyday problems, it may be possible to break out of the trap created by years of effort at superficial causes.

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* Whitehead, A. (1925). *Science and the modern world.* New York: Macmillan. Chapter 4.

Dealing more effectively with failures of integrity

Thought Experiment

One state allocates about $1,000 per client for case management services. State rules make case managers responsible for insuring that each of their clients has an appropriate individual service plan, which state statute defines as central to effectively coordinated, individualized services. Case managers are also responsible for representing their clients interests in a variety of other ways and are defined, by law, as independent of service providers.

Consider this alternative to the state's present practice of licensing and routinely inspecting services.

- The state repeals its licensure law and all related regulations for people who have case managers. The state keeps the authority to prosecute for abuse or neglect of vulnerable adults with developmental disabilities and provides the state developmental disabilities agency with the duty and the capacity to discover and investigate complaints of abuse and neglect.
- Case managers are required, every six months, to file a form for each client on their caseloads. On this form they affirm that they have current personal knowledge of the person's living situation and that either a) they can affirm that the person is living in safe and decent conditions, that the person's money is appropriately managed, that the person is receiving needed health and dental care, and that the person is receiving at least minimally adequate assistance to deal with the consequences and vulnerabilities of the person's particular disability, or b) if one or more of these conditions is not met that they are personally involved in efforts to insure that they are met. This form is also co-signed by involved service providers. Copies of the form would go to the person and to involved family members or guardians.
- As a condition of funding, service providers would summarize the findings of case mangers and describe the influence these have on their operations.
- Responsible state managers would audit a random sample, say 5%, of these forms by accompanying the responsible case manager to visit the person involved and noting agreement or disagreement with case manager judgments on the form. Concerns about case management judgments will become part of case management contract negotiations.
- A person who is the subject of this form who feels unsafe, or anyone who has reason to be concerned for the person's safety, can compel a timely audit of the situation by responsible state managers.

Is this an adequate replacement for licensing inspections?

A number of people say "no" to this proposition for these reasons: case managers have case loads which are too large to permit them to know whether or not the people on their case loads are safe; case managers may be in conflict of interest and thus unreliable judges of people's safety; and case managers lack the authority to compel unwilling service providers to listen to them about safety problems.

If these arguments against assigning responsibility for safety to case managers seem persuasive, what reasons remain for funding case management? How can someone who cannot be trusted to know about and act to uphold people's physical safety be trusted with authority to plan for their lives? How can someone who lacks the ability or authority to negotiate with service providers be an adequate coordinator of a complex service plan?

People who provide assistance can fail in integrity in three different ways: they can act without integrity by overtly abusing or neglecting people with developmental disabilities; they can defraud by misdirecting funds allocated to assist people for personal gain; and, they can fail in the particulars of integrity through closedness, or lack of consciousness, or failure of action. Mixing up the first two kinds of failures, which are criminal, with the third, which is not, results in driving the service system deeper into the fear and inflexibility which will defeat the spread of effectively interdependent relationships.

Being fair and clear by not over identifying abuse and fraud

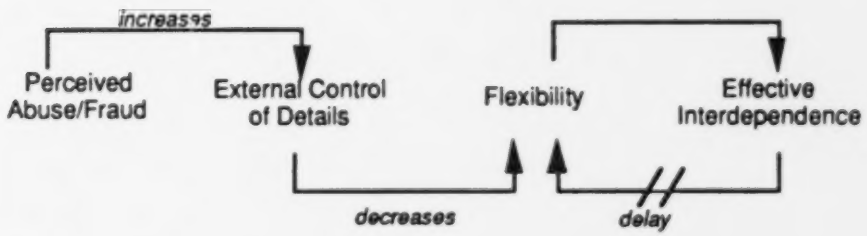
It is worth noticing that the notion of abuse has undergone considerable inflation over the last twenty years, usually by people deeply concerned about the effects of ingrained discrimination. Thus, some people speak of congregate settings, and the people who work in them, as abusive; some regard failure to respect a person's choices as abusive; and some identify the use of disrespectful language, such as labeling a person "mentally retarded," as abusive. An inflated definition of abuse has two unfortunate consequences: it invites the invocation of drastic threats for behavior that many people can't yet see the harm in; and, it numbs sensitivity and blunts responsiveness to obviously horrible circumstances.

While granting the hurt in congregating people, denying them choice and labeling them disrespectfully, it is important to distinguish these failures in the particulars of integrity from beating

people, letting or even encouraging people to prey on one another, locking or tying people up, starving people, denying people medical care, letting people lie unattended in their own urine, stealing people's money, or cruelly depriving people of their possessions, their freedom of movement, or their freedom of association, keeping people sweltering or cold or in obviously unsafe premises. In short, abuse and neglect should be defined in a way that any citizen on a jury could agree was a reprehensible way to treat a human being.

The notion of fraud is sometimes similarly inflated, often by people in oversight roles who seek to expand their power over the transactions of operating departments. Labeling more fraud justifies transferring power away from operationally responsible managers and toward inspectors, analysts and auditors. Whether this desire for more power over details comes from a belief that public purposes will be better served, or from more partisan motives, it can lead auditors and analysts to classify differences of opinion about legitimate expenditures or paperwork errors in the same category as charging a manager's Florida vacation home off to client care or paying physicians for medical tests they never made. In the interest of fairness and clear thinking, fraud should only be invoked in a context where there are sufficient grounds for criminal prosecution.

Zealous over-identification of abuse and fraud detracts from effective interdependence:



Greater flexibility increases the chances that people will form effective interdependent relationships and, over time, more effective interdependence increases flexibility. But, as external oversight and control of the details of assistance increases, the chances that service providers will behave flexibly in response to changing situations decreases. Decreased flexibility decreases effective

interdependence. An increase in perceived abuse or fraud increases the chances of external control and thus decreases flexibility and then decreases effective interdependence. This picture argues for preservation of flexibility by 1) avoiding inflated reports of abuse and fraud, no matter how politically useful such exaggeration might be in the short run; and, 2) finding alternatives to external oversight and control of details as a response to those service providers who simply lack integrity.

Dealing with those who lack integrity

Unfortunately, as a consequence of the social devaluation of people with developmental disabilities, services can attract people who are outright abusive or neglectful. Abuse and neglect usually results from laziness and self-centeredness, but it can be an expression of cruelty. Whatever its motive, it is simply wrong and best seen and treated as an offense against the law.

There are at least three components of an effective police power.* First, entrench a clear and well publicized duty to report the abuse and neglect of vulnerable people, including protection of whistleblowers and the well publicized imposition of fines or other penalties on authorized people who fail to report long-standing patterns of abuse which they have a duty to know about (say, the dentist who has an investment in a nursing home, the board chair or director of a non-profit agency, or the abused or neglected person's case manager). As part of their orientation to work, new staff should have the opportunity to review the facts and the disposition of a variety of cases of abuse and neglect, perhaps in the format of a "true crime" TV show. Second, invest in the capacity for timely investigation and effective prosecution of abusive or neglectful conduct. Law enforcement overload, and widespread insensitivity to the humanity of people with developmental disabilities among law officers and prosecutors, may argue for investigators, and even prosecutors dedicated to this activity.

The third, and perhaps most problematic, component of an effective response to abuse and neglect is the capacity to generate alternative assistance and, in the case of people housed by their

* This discussion is very sketchy because our purpose is to indicate direction, not to substitute for the debate and experimentation necessary to police abuse and neglect. For example, we neglect the vital issue of protecting the unjustly accused.

abusers, alternative living arrangements. Inability to create alternatives hamstrings efforts at protection. When system managers can offer no other, safer roof to sleep under, people with developmental disabilities are hostages to those who would abuse or neglect them.* Painful pressures constrain this capacity: growing and increasingly urgent waiting lists, small increases in unrestricted funding, and deals that target growth in system capacity to particular classes of people (e.g. residents of an institution which is permitted to continue receiving federal funds on condition of population decline, or residents of nursing homes disinterested in meeting requirements to provide active treatment to people with developmental disabilities). All of these pressures of overcommitment contribute to managerial problems that can become living nightmares for people with developmental disabilities.

In addition to these powers, careful, external review of the circumstances of death for every person served by the system provides important knowledge to improve practice as well as offering some possibility of detecting abusive or neglectful practices.

There are dishonest people who steal public money from people with developmental disabilities. Given sensible contracts which recognize the need for flexible assistance, and given straightforward bookkeeping and reporting requirements, detecting and decreasing this kind of theft should be seen as a problem of auditing, detecting fraud, and enforcing its penalties.

If the system lacks an effective police power, people with developmental disabilities and their families and friends should know it and they should not allow the politicians they elect or the administrators they appoint to hide this lack in a fog of rules, regulations, and inspections.

* See Bardach, E. (1977). *The implementation game: What happens when a bill becomes a law?* Cambridge, MA: MIT Press. Bardach analyzes California's Lanterman Act and in Appendix B, An alternative to licensing, he cogently argues that without slack resources, i.e. an oversupply of residential services, the system will be hostage to its providers, no matter how detailed the regulations or how fierce the inspectors or how detailed the individual service plans.

Dealing with those who need to learn

Thought Experiment

One state relies very heavily on a large residential service provider whose many programs are regularly inspected by several different regulators. Over several years, this provider continued to operate and to expand, dealing successfully with a variety of regulatory processes, including, for a number of residents, a process that involves regular review of individual situations by inspectors selected for their programmatic skill and understanding of state of the art service practices.

These inspections apparently failed to effectively focus the provider management's attention on an organization-wide pattern of negative practices and apparently failed to effectively alert funders to a long term pattern of mis-management which threatened the organization's viability. (I use the modifier "effectively" because I don't want to imply that inspectors necessarily were unaware of problems or didn't raise concerns, only that, whatever was done, it didn't work.)

An external team of 35 people, most of whom volunteered their time, visited 72 program sites and interviewed 161 individuals assisted by the agency. This process, commissioned by provider board members, shocked and stimulated the agency's board and central managers with its findings and has provided a framework for attempts to regain direction.

What justifies the continuing expenditure of extremely scarce public funds on the time of inspectors and the time of provider staff in the pursuit of routine documentation, planning processes, inspections, and correction activities that over a period of at least five years, failed to effectively identify these issues?

Given that the inspectors presently have the authority to identify most if not all of the problems surfaced by the external team, and given that the inspectors are capable of carrying out their duties (indeed, many of them are highly skilled people who are personally committed to improving life for people with developmental disabilities), does it make sense to conclude that this case justifies more regulatory authority, more investment in inspections and inspectors, or more training for inspectors?

If you had been on a waiting list for services for the years these situations went unmanaged, would you feel that the public money spent on compliance activities for this provider was well spent?

If offered a home by this provider, would you feel secure and comfortable because inspectors visit regularly?

When the system develops the capacity to treat criminals as criminals, the willfully abusive and neglectful can be detected and removed from the field. That will leave the rest of us: well intentioned and fallible people who need to learn to be more effectively interdependent.

Because we have grown up in a culture that devalues people with developmental disabilities, we must continuously raise our consciousness of the many ways we reproduce this devaluation. Debate and action to raise consciousness and change unjust social patterns forms the context for confronting one another about disrespectful language and thought patterns, about ignoring the opportunities sacrificed when services segregate and congregate people with developmental disabilities, for underestimating people's abilities, for narrowing people's exercise of their rights. Here is the context for debate over the relative costs and benefits of different solutions to the many problems of assuring people assistance focused on opportunity.

Because many of us incline to individualism and self-centeredness, we must continually learn to open our hearts to the voices of people with developmental disabilities and the needs of our whole communities. Such listening provides the context for us to guide one another to understand the ways our life stories interweave with those of the people we assist, to listen with our hearts and our arms and legs as well as with our ears and minds, to invite other citizens to share the lives and interests of people with developmental disabilities. Here is the context for us to deepen our understanding of ourselves, of one another, and of the emerging meaning of community in this age of individual freedom.

Because we find ourselves enmeshed in a thousand good reasons not to take any action which will disrupt things by opening up a new opportunity to a person with a developmental disability, and because every action has its shadow of imperfect realization and unintended consequence, we must continually learn to join more effectively with people with developmental disabilities and their families and friends to make changes. These relationships provide the context for us to encourage one another to act on what we say we believe, to reflect on what we have learned from the results of our action, to plan in ways that involve widening circles of people in making change. Here is the context for thoughtful experimenta-

tion, in company with people with developmental disabilities, which will help us figure out how to overcome the next set of barriers and realize the next opportunity.

These forms of learning cannot be coerced; they require that people commit from freedom. No matter how sensitive the practitioner of regulation, the gesture of regulating kills the kind of learning necessary to increased consciousness, greater heart, and better aligned action for change.

Those who want to nurture learning for greater integrity will invest substantially in some things and stop doing others. They will invest substantially in...

...many ways to strengthen the voices of people with developmental disabilities including funding, developing and encouraging...

- organizations (like People First) independent of service settings
- peer counseling of the sort practiced successfully in many Centers for Independent Living
- organizations of people with developmental disabilities to develop their own learning activities, their own perspectives on policy, and their own alliances
- extensive experiments to discover ways to facilitate effective participation in planning and governance activities

...many kinds of consultations and evaluations invited by involved people

...many kinds of occasions for study of the history and dynamics of social devaluation and the ways service practices unthinkingly reproduce social devaluation

...careful study of actual instances of abuse, neglect, and fraud and wide dissemination of analysis of their causes and consequences

...many opportunities to study and debate the growing base of practical knowledge relevant to providing good assistance

...many opportunities to form mutually supportive and mutually challenging relationships with others in the same work

Those who want to nurture learning for integrity will stop...

...trying to coerce consciousness, openness, and action, in favor of openly inviting and joining actively in learning

...trying to manipulate people into assent to what seems like a positive vision, in favor of clearly communicating one's own vision and actively inviting others to link their visions to it

...trying to use regulatory authority in place of open attempts at persuasion and principled negotiation

The means to learning for effective interdependence are not esoteric. Anyone who can keep the elements of integrity –consciousness, openness, and action– at the center of their work for even a moment will learn enough to take the next step.

The potential contribution of "Total Quality Management"

Total Quality Management (TQM), and its many acronymed cousins, has gained currency as a way out of the regulation trap. Many state human service bureaucracies have embraced some process for "continuous improvement" as a complement to the work of its inspectors. A thorough assessment of this growing investment in quality improvement activities is beyond our present scope, but we will briefly identify what we believe is its greatest potential contribution.

W. Edwards Demming, one of the most frequently cited leaders of the move toward better quality, outlines the greatest contribution of TQM in his "Principles for Transformation,"* in particular his "14 Points for Management." It appears that Demming's ideas about the role of management get much less attention than the techniques of statistically based problem solving for front line workers derived, in part, from his work.

In Demming's view, these techniques for controlling variation do not contribute to a system's effectiveness until that system's manag-

* Demming, W. (1986). *Out of the crisis.* Cambridge, MA: MIT Center for Advanced Engineering Study. Chapter 2.

ers have developed the system to the point that it routinely produces socially valuable results in a stable fashion. This clarifies a major challenge to quality improvement initiatives in developmental service systems which spend the great majority of their budgets on services that do not support effective interdependence. Services based on the dominant pattern of bureaucratic, professional work to fix defective people cannot improve the details of their performance until they transform the design of their services and the nature of their relationship with the people with developmental disabilities who rely on them. Services which have not developed a consistent process for assisting people to discover and develop new opportunities for themselves, must focus on this before they choose narrow gage improvement projects.

Thoughtful consideration of several of the "14 Points for Management" would, it seems to us, support our position that the inspection-correction approach has long since outlived its usefulness.

Thought Experiment

Develop a compelling argument *against* these three of Demming's "Points for Management."

3. Cease dependence on inspection to improve quality. Eliminate the need for inspection on a mass basis by building quality into the product in the first place.

8. Drive out fear, so that everyone may work effectively for the company.

10. Eliminate slogans, exhortations, and targets for the work force asking for zero defects and new levels of productivity. Such exhortations only create adversarial relationships, as the bulk of the causes of low quality and low productivity belong to the system and thus lie beyond the power of the work force.

Perhaps the most helpful insight Demming offers into organizational transformation comes from his insistence that leaders can only improve quality if they are continually deepening their understanding of the particular system they are leading. Better quality does not result from technique but from immersion in thinking about, experimenting with, and learning from and about the system one leads.

Building on this insight, Kim and Burchill demonstrate the usefulness of clearly identifying some of the key relationships that are likely to limit quality improvement.* Following their example, we would identify two crucial, interrelated limits to the growth of effective interdependence in services to people with developmental disabilities.

- Effective interdependence can only grow as long as there are agencies willing to redesign their work and restructure their organizations to support learning with people with developmental disabilities about how to increase community opportunities relevant to their capacities and interests. This learning process generates small, personally focused support systems which organize and reorganize in response to changing personal and community circumstances. There probably is a limit to the number of agencies ready to redirect themselves, so the number of good examples can be expected to grow rapidly for a while and then taper off until less venturesome agencies join the move.
- The number of agencies willing to restructure and redesign themselves depends, in significant part, on the degree of coercion exercised by the larger system. The more coercion, the more defensive behavior, including such ploys as re-labeling business as usual with desired terms, bargaining to establish that business as usual is what people with developmental disabilities need or want, and developing counter threats through expansion and coalition. The more coercion, the less learning.

This simple analysis suggests that there may be significant leverage in system administrators shifting from coercive measures to persuasive approaches. For example...

...moving quality improvement from an externally enforced requirement to an explicit part of contract negotiation

...finding a variety of ways to enroll agency leaders in the pursuit of effective interdependence

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* Kim, D. & Burchill, G. (1992). *Systems archetypes as a diagnostic tool: A field based study of TQM implementations.* Systems Dynamics Group Working Paper D-4289. Cambridge, MA: MIT Sloan School of Management.

...strengthening the presence of people with disabilities in the contracting process

...increasing the opportunities for people to start up new agencies

...developing ways to build networks of people committed to learning how to organize to increase effective interdependence.

Regulating the field by shared learning and explicit negotiation may seem slower than requiring new structures, but, in the long run, it may be no slower than the effects of trying to push people into learning against their will.

Integrity as a guide to policy

Staff people committed to effective interdependence see their relationships in ethical rather than technical terms. They feel called on to figure out how to do the right thing, from the point of view of personal caring and justice; not the correct thing, from the point of view of state or federal regulations. They refrain from harming people not because harming people would break a rule, but because they care for people. They do not steal because they are generally honest, not because they fear being caught. They are respectful not because of rules but because they know people as people. They do not respond positively to people with developmental disabilities because it is required by their job description. They keep their jobs (sometimes in spite of their job descriptions) because their jobs provide opportunities to do positive things with people with developmental disabilities.

The resources represented by people who provide services with honesty, care, personal knowledge, and commitment to active, ethical problem solving are valuable beyond computation. Any meaningful change in the devalued social status of people with developmental disabilities depends, in significant part, on these resources.

But these precious resources are easily discounted, and thereby greatly diminished in their effects. Facile administrators and legislators, preoccupied with stereotypes of wasteful and abusive providers, add more procedures and more rules in response to scandals, crises, and reform efforts. When challenged, they point

triumphantly to those who commit abuse, and they smugly remind the challenger that the taxpayer demands accountability for the expenditure of public funds. This self-righteous attitude is sealed in place with the uncritical belief that good people will have no trouble following the rules. They may complain, goes the complacent refrain, but they will comply.

Beyond the plain bad manners of taking people's commitment for granted, this short sighted approach erodes the foundation for good quality services. It powerfully shapes the climate and the norms within which services develop and operate, signaling that conformity with bureaucratic specifications for professional activity is sufficient for effective service. It contributes to public and legislative cynicism by interpreting service workers as venal, lazy, and stupid. It drives up transaction costs: even the simplest changes are made more complex. And, it generates conflict, defensive behavior, and disrespect for the system when what is correct, according to the rules, either doesn't fit the demands of a particular person's circumstances or is patently foolish (like the inspector's oddly metaphysical judgment: "If it's not documented, it wasn't done). Coercive techniques make no more sense, and are no more right, when they are applied across the board to staff and agencies than they do when they are applied to people with developmental disabilities.*

As these effects of assuming untrustworthiness accumulate, the phenomenon of adverse selection begins to take effect. A climate of distrust, defensiveness, and insistence on formal correctness at the expense of initiative has powerful long term effects on recruitment. Public administration theorists use the term "adverse selection" to describe this process: the environment begins to select for agencies and people who find comfort and reward in compliance for its own sake. Such agencies and such people can, at their best, be no more than ploddingly humane keepers. They cannot contribute to the work of increasing the measure of everyday justice available to people with developmental disabilities.

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* For a persuasive application of this basic lesson of applied behavioral analysis, and a description of the tremendous costs of ignoring it, in organizational life and policy analysis, see Sidman, M. (1989). *Coercion and its fallout.* Boston: Authors Cooperative Press. Sidman's analysis helpfully complements the revolutionary position on management taken by W. Edwards Demming

Alexis de Tocqueville wrote in 1840 about the sort of despotism which the participants in the American democratic experiment should fear. It's worth comparing regulated life for people with developmental disabilities and those who assist them with his speculation:

> *[This] immense and tutelary power... covers the surface of society with a network of small complicated rules, minute and uniform, through which the most original minds and the most energetic characters cannot penetrate... The will of man [sic] is not shattered, but softened, bent, and guided; men are seldom forced by it to act, but they are constantly restrained from acting: such a power does not destroy, but it prevents existence; it does not tyrannize, but it compresses, enervates, extinguishes, and stupefies... people, till t[hey are] reduced to be nothing better than a flock of timid and industrious animals, of which the government is the shepherd*

Leaders who want an alternative to this form of paralysis can have one, at a price. They must risk making it plain that the safety of people with developmental disabilities, and the quality of the assistance they receive, depends mostly on civic virtue, and particularly on the personal and organizational integrity of those who provide publicly funded assistance.* They must risk acknowledging that bureaucratic organizational principles apply so poorly to supporting changing lives in changing communities that people with developmental disabilities can only have decent quality services when those who provide them let go of bureaucracy in favor of organizational forms which are more flexible and better able to support learning. In short, bureaucrats must publicly and consistently call attention to the fact that all the bureaucratic new clothes the emperor has been buying for the past forty years have long since ceased to provide relevant cover.

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* See Garvey, G. (1993). *Facing the bureaucracy: Living and dying in a public agency.* San Francisco: Jossey Bass, Chapters 9 &10 for a brief but helpful discussion of these points from the point of view of public administration theory.